

After "Eve": Whither proxy decision-making?

Eike-Henner W. Kluge, PhD

One of the most difficult problems facing physicians is how to approach proxy decisions made on behalf of congenitally incompetent patients. The author considers two recent court cases that attempt to provide guidelines: *Re Stephen Dawson*, which opts for a substituted-judgement approach, and *Eve v. Mrs. E.*, which enjoins best-interests considerations. The author explores the impact of *Eve v. Mrs. E.* as superseding *Re Stephen Dawson*, considers its ethical implications and attempts to clarify the best-interests criterion by sketching some guidelines for its interpretation. In so doing, he tries to reconcile the two decisions by laying bare their common underlying ethical rationale. The author concludes by pointing out some ethically questionable implications of *Eve v. Mrs. E.* in the area of allocation of health care resources.

L'attitude à tenir devant les décisions qui ont été prises par procuration à l'égard de personnes congénitalement inaptes constitue l'un des plus graves problèmes auxquels le médecin peut être confronté. Présentation de deux cas récents où la cour a cherché à définir des directives. Dans la cause de Stephen Dawson on avait opté pour un jugement substitutif; dans *Eve contre Mrs. E.* on préconise comme guide le meilleur intérêt du sujet. L'auteur examine la question de savoir si le second critère remplace le premier, en analyse les conséquences éthiques et esquisse une manière de l'interpréter. Il en vient ainsi à concilier ces deux jugements, en montrant leurs fondements éthiques communs. Enfin il formule des doutes quant aux conséquences éthiques de *Eve*

contre Mrs. E. pour ce qui est de l'affectation des ressources sanitaires.

One of the most difficult situations that physicians may face is one involving an incompetent patient. Normally, following what could be called a fiduciary model of the physician-patient relationship, physicians may feel that they have fulfilled their professional obligation when they have advised the patient of the various pertinent modalities of treatment, expressed an opinion and made a recommendation, and have done all this in language that the patient can and does understand. Whatever decision the patient then makes will be legally and ethically acceptable. If it should not accord with the physician's own better judgement, he or she may of course attempt to reason and persuade but not coerce; and all other things being equal, the physician may not overrule the patient's determination. *Reibl v. Hughes*¹ is very clear on that point. If all else fails and the physician cannot in good conscience accept the patient's decision, there is always the option of referring the patient to another physician and withdrawing from the case.² At no point, however, with the exceptions of emergency and therapeutic privilege, is the physician called on to assume the role of proxy decision-maker or to examine the ethical acceptability of the decision itself.

The case of the incompetent patient, however, is different. Here the physician must assume an evaluative role. As front-line workers, so to speak, physicians have to examine the way in which the proxy decision-makers — usually the next-of-kin — make the decision in order to assure themselves that it is the product of reflective consideration and not the offhand result of a hasty reaction. Furthermore, they must consider the criteria used by the proxy decision-makers in reaching the decision in order to make sure that they do not simply reflect the proxies' own standards, feelings or expecta-

Dr. Kluge is a professor and consultant in medical ethics, Department of Philosophy, University of Victoria.

Reprint requests to: Dr. Eike-Henner W. Kluge, Department of Philosophy, University of Victoria, PO Box 1700, Victoria, BC V8W 2Y2

tions but rather are ethically appropriate. When there is any doubt, the physician must engage the appropriate administrative or legal channels to prevent what may be an unacceptable exercise of proxy authority.³

To some degree, of course, this is a matter of subjective assessment on the part of the physician, but not entirely so. In cases in which the patient was once competent but is competent no longer, the physician will balance the quality of life expected from the various treatment options against the wishes and expectations expressed by the patient when competent in order to assess the reasonableness or acceptability of the particular proxy decision. The testimony of next-of-kin as well as formal and informal data to which the physician may have access will provide invaluable assistance. As to situations in which there is no evidence that the patient expressed preferences when competent, the physician will proceed on the basis of the quality-of-life standards that are currently accepted by the ordinary person, standards that are based not on the concept of social utility (whether defined within the ambit of the immediate family or social grouping or drawn more widely to include society as a whole) but rather on criteria that flow from the concept of the patient as a person. The physician will take into account the distinction between the continuation or sustaining of merely biologic life and support of the patient as a person who has (or retains the capacity for) sapient cognitive awareness and the possibility of meaningful social interaction.⁴ Again, while this will involve a certain amount of subjectivity on the part of the physician, it need not and does not occur in complete isolation. Physicians can draw on the more or less standard perception of quality of life that prevails in society and are aided by their sensitivity to the cost of the various treatment options to the patient in purely human terms. Their professional knowledge of the nature and likelihood of the outcomes expected from the various modalities of treatment is invaluable, as is their awareness of what other, competent patients under similar circumstances have decided. Together, all this gives the physician a fairly good idea of what the ordinary reasonable person would decide under similar circumstances and provides a basis against which to measure the proxy decision. And although this sort of approach may present difficulties on occasion, it generally is workable and presents no serious ethical problems.

As to the case of the currently incompetent patient who never has been competent but in all likelihood will become competent in the future — i.e., an otherwise normal child — it, too, does not present the physician with fundamentally new issues. The physician will proceed on the assumption that, all other things being equal, the child's sensible experience and qualitative perception of the world is essentially like that of an adult and that the factor of incompetence involves the cognitive and judgemental plane. It is therefore entirely

appropriate for the physician to take into account the child's subjective expressions (in so far as they are present or available) and balance them against the objective standard of what a reasonable person would decide when considering the proxy decision. The function of the proxy is to supply the cognitive and judgemental want of the child. Consequently, if the physician finds that the proxy decision-maker has introduced his or her own, nonstandard values in making the decision, the physician must challenge the decision. The situation becomes a little more complicated when the child has given assent in a particular direction, but even here it is not a matter of purely subjective evaluation. The assent must be seen as guiding, although not necessarily determining, depending on the facts of the cases.^{5,6} Finally, in all cases of doubt, the courts must be the ultimate forum of appeal.

The radically congenitally incompetent patient

The case of the congenitally incompetent patient who, so far as medical science can tell, not only is barely at the limits of sapient cognitive awareness but also in all probability will never become competent is radically different. The sort of balancing of subjective expression against an objective standard that can at least be attempted in other cases seems inappropriate here. This is so not because the patient is not reasonable — no incompetent patient is — but because the presumption on which such balancing is based may be false in such cases. The quality of life of the radically congenitally incompetent patient may be so fundamentally different from the norm that both the use of the objective standard of what a reasonable person would decide as a balance and the attempt to use the patient's own subjective expression would be untoward. The very significance of the latter may be fundamentally misconstrued because it would be based on the world experience of the physician, someone who fits the norm of the reasonable person. Consequently, there exists a danger that the use of the objective standard would violate the individuality of the patient and that the attempt to circumvent this by using subjective indicators from the patient would be so out of line with his or her actual experience that any treatment decision based on these criteria would be experienced as cruel and unusual treatment.^{7,8}

If this is true, the physician who monitors proxy decisions made for radically congenitally incompetent patients is faced with a serious problem: What criteria — indeed, what evaluative approach — ought he or she to apply?

The Stephen Dawson decision

It was at least in part for this reason that the

1983 British Columbia Supreme Court decision *Re Stephen Dawson*⁹ was welcomed by some members of the medical community. The case concerned a 7-year-old boy who had contracted meningitis shortly after birth, suffered severe brain damage and become hydrocephalic and as a consequence was exceedingly retarded, with no control over his faculties or limbs. At 5 months of age a shunt had been inserted and had been revised over the years, and at the time of application to the courts revision was again required. The reason for the court intervention was that the parents, as proxy decision-maker, had initially agreed to the revision, but after taking into account what they considered to be appropriate quality-of-life considerations from the perspective of the ordinary person — considerations involving the capacity for sapient cognitive awareness, the possibility of relatively pain-free and physically comfortable existence, and the potential for meaningful social interaction — and after consultation with a pediatric neurosurgeon they had withdrawn their permission. The superintendent of child welfare for the province intervened, and the matter came to trial in provincial court. The test used by the court to evaluate the parents' decision was whether, under the circumstances, the proposed revision constituted extraordinary treatment. The court decided in the affirmative and held in favour of the parents. On appeal to the British Columbia Supreme Court, the decision was reversed and an order for treatment was made. Stephen subsequently received treatment and continues to live.

It was the reasoning stated by the British Columbia Supreme Court that made the decision so important for the medical community. For the first time in Canadian medicolegal history the courts issued a ruling that explicitly addressed the question of what criteria and approach a proxy decision-maker and a physician should use when dealing with a congenitally incompetent person. Mr. Justice L. McKenzie, who decided the issue, ruled 1) that a congenitally incompetent person does not lose the rights to health care normally enjoyed by other persons simply in virtue of his or her incompetence, 2) that the duty of exercising this right normally rests in the parents as appropriate proxy decision-makers, 3) that their decision-making authority is appropriately challenged when it is not exercised in the best interests of the incompetent person, and 4) that what counts as being in the best interests of the incompetent person must not be determined from the point of view of the objective reasonable person. Rather, 5) it must be determined from the perspective of the incompetent person. As Judge McKenzie put it, "I do not think that it lies within the prerogative of any parent or of this court to look down upon a disadvantaged person and judge the quality of that person's life to be so low as not to be deserving of continuance." Quoting with approval Judge Asch in the US case *In the Matter of Eugene Weberlist* ("In this case, the court must decide what its ward

would choose, if he were in a position to make a sound judgment.") he went on to say:

This last sentence puts it right. It is not appropriate for an external decision-maker to apply his standards of what constitutes a livable life and exercise the right to impose death if that standard is not met in his estimation. The decision can only be made in the context of the disabled person viewing the worthwhileness or otherwise of his life in its own context as a disabled person — and in that context he would not compare his life with that of a person enjoying normal advantages. He would know nothing of a normal person's life having never experienced it.

In adopting this position, Judge McKenzie was enunciating what had become known as a substituted-judgement approach to proxy decision-making for congenitally incompetent persons. As one US commentator put it, proxy decision-makers should try to put themselves as much as possible into the situation of the incompetent person and then decide in the way and from the perspective from which the latter would decide, were he or she able.¹⁰

The Stephen Dawson case injected an element of clarity into the Canadian context. The Canadian physician faced with the question of how to proceed in these sorts of cases now had definite guidelines on how to interpret "best interests" considerations and evaluate the appropriateness of a particular proxy decision. However, while definitive and clarifying, Judge McKenzie's decision was not without problems, some of which I pointed out at the time.¹¹ In the context of proxy decision-making the most important problem was the concept of a substituted-judgement approach itself. As I said then, the demand that the perspective of the congenitally incompetent person should constitute the basis of quality-of-life considerations by the proxy decision-maker and that any acceptance or rejection of medical treatment should be grounded on this basis is not only unworkable in practical terms but also and, indeed, above all logically incoherent. If the incompetent person lacks sapient cognitive awareness — or, less severely, if he or she lacks any standards or criteria — then, trivially, neither standards nor criteria can be ascribed to the person. That fact is definitive of the situation in which such people find themselves and characterizes their very nature. It is therefore logically impossible to determine what their wishes are or would be if they could make them known. To proceed otherwise is to do one of two things: to assume that despite this lack they have standards or criteria after all — a flat contradiction — or to project some other standards or criteria into the situation by substitution and thereby treat incompetent people as though they were not incompetent. In either case, however, the very concept of substituted judgement, of viewing the situation from the perspective of the incompetent person, "in its own context", is a fiction.

If this analysis was correct, the position of the physician faced with a congenitally incompetent patient was not improved but rather was worsened by the Stephen Dawson case: uncertainty over how to proceed had indeed been replaced by certainty, but at the price of logical impossibility.

The case of "Eve"

Then came *Eve v. Mrs. E.*¹² which altered the whole picture. On the facts, the case was entirely different from that of Stephen Dawson. "Eve" was a 24-year-old moderately retarded woman suffering from extreme expressive aphasia. She was described to the courts as an extremely pleasant and affectionate person who, being physically adult, was capable of being attractive to and attracted by men. Her mother, of advancing years, feared that Eve might become pregnant, and since Eve was unable to take care of a child, the mother saw herself faced with the prospect of having to care for Eve's progeny. She found this unmanageable. She also felt that both pregnancy and childbirth would be incomprehensible to Eve. Consequently, acting as proxy decision-maker, she requested that Eve be sterilized.

The court of first instance rejected the request. It ruled that except for clinically therapeutic reasons, parents or other appropriate proxy decision-makers could not give valid proxy consent to such a procedure. On appeal to the Supreme Court of Prince Edward Island, the judgement was reversed and sterilization by hysterectomy was ordered. However, leave was granted to appeal the decision to the Supreme Court of Canada. On Oct. 23, 1986, that court handed down its ruling. It reinstated the trial court's order and rejected sterilization. Mr. Justice La Forest, writing the unanimous decision of the court, gave two reasons. One dealt with the historical nature of the *parens patriae* powers of the court. Here the thrust of Mr. Justice La Forest's deliberations was that these powers could be exercised only in the best interests of the incompetent person, no matter what the position of society or next-of-kin. The second reason was an attempt to clarify the way in which such best interests could be determined. He here focused on the position advanced by the attorneys for Mrs. E. They had argued that as proxy decision-maker Mrs. E. had the duty to exercise Eve's rights for her and had argued further that, indeed, these rights ought to be exercised on the basis of what would be in Eve's best interests. However, they insisted that Eve's best interests could be determined only in a subjective fashion: by approximating as closely as possible the kind of situation in which Eve found herself and then making the kind of decision that she herself would make. In other words, they reasoned that a "substituted-judgement" approach to the determination of "best interests" would be appropriate "because it places a higher value on the individuality of the incompetent person".¹²

Using such an approach, they argued, would result in a decision for sterilization.

For the purposes of this essay, it is irrelevant whether the logic of Mrs. E.'s position is valid. What is important is the court's reaction to the line of reasoning. While accepting the concept of best interests as appropriate, the court roundly rejected the contention that best interests could be appropriately determined with the substituted-judgement approach. In fact, the court brusquely rejected the concept of substituted judgement itself. Substituted judgement, it reasoned, is an attempt to determine what choice the incompetent person would make were he or she able. However, the court stated,¹²

Choice presupposes that a person has the mental competence to make it. It may be a matter of debate whether a court should have the power to make the decision if that person lacks the mental capacities to do so. But it is obviously a fiction to suggest that a decision so made is that of the incompetent, however much the court may try to put itself in her place. What the incompetent would do if she or he could make a choice is simply a matter of speculation.

Mr. Justice La Forest went on to speak of "the sophistry embodied in the argument favouring substituted judgment" and quoted with approval from *Matter of Eberhardy* (a US case), in which the court had stated:¹³

We conclude that the question is not choice because it is sophistry to refer to it as such, but rather the question is whether there is a method by which others, acting on behalf of the person's best interests and in the interests, such as they may be, of the state, can exercise the decision.

Neither the US court nor the Supreme Court of Canada went on to detail such a method. They agreed in their focus on best interests considerations. One thing, however, was clear: by characterizing the substituted-judgement approach as legal "legerdemain", the Supreme Court effectively ruled out the very test enjoined by the Stephen Dawson case.

Of course, it could be argued that all this holds only for sterilization, that it leaves all other cases unaffected. That, however, is unlikely for three reasons. First, it would contradict the very *raison d'être* of Supreme Court decisions. They are, and are supposed to be, models for general types of cases. While *Eve v. Mrs. E.* is representative of sterilization cases, it is also and, indeed, above all representative of a type of case that deals with the problem of proxy decision-making for incompetent people. All cases of proxy decision for such people are thereby affected. The fact that the court itself saw it in this light is evidenced by the fact that the precedential cases it considered and cited in reach-

ing its decision were drawn from a whole spectrum of cases proposing medical procedures for incompetent people, not only those advocating sterilization. Second, the fact that the Supreme Court intended its decision to have wider ambit is indicated by the fact that its rejection of substituted judgement is not explicitly directed to sterilization cases. It is couched independently of that issue in response to the argument that a substituted-judgement approach as such "is to be preferred to the best interests test because it places a higher value on the individuality of the mentally incompetent person".¹² In other words, it was a reply to the argument that because the substituted-judgement approach is the appropriate test for incompetent people in general, it should also be used in this case. It is to this general claim that the court replied in the negative. Its rejection, therefore, has general implications. Finally, there is this to consider. Undoubtedly there are many strands intertwined in this case. However, to construe the rejection of substituted judgement in a limited fashion is to ascribe to the Supreme Court the position that different principles of law and of ethics hold for the very same problem — proxy decision-making — in different material cases. Not only would that undermine the very notion of the uniformity of legal and ethical principles, but also it lacks basis in any of the court's dicta.

I suggest, therefore, that *Eve v. Mrs. E.* ought to be seen as having general import. But if that is the case, it presents the Canadian physician with a problem: How to interpret best interests? The fact that the court recalled with approval Lord Eldon's remarks in *Wellesley v. Wellesley* ("It has always been the principle of this court, not to risk damage to children . . . which it cannot repair"¹²) may be considered guiding. However, that merely pushes the interpretational uncertainty onto the word "damage". Did the court intend this to apply to physiologic damage only, or did it intend to encompass psychologic, mental and emotional deficit as well as other repercussions? There are indications that it intended the wider construal; for example, it inveighed against a "grave intrusion on the physical and mental integrity of the person"¹² and included "health problems, religious upbringing and protection against harmful association".¹² But we do lack a really explicit statement. The physician is thus once again left in a domain of uncertainty. Only three — negative — guidelines are clear: physicians may not use a substituted-judgement approach to evaluate the appropriateness of proxy decisions, they may not accept a decision based on the proxy decision-maker's own idiosyncratic standards, and they may not use their own values, standards and expectations.

Attempt at a resolution

However, both the reasoning advanced in *Re Stephen Dawson* and that given in *Eve v. Mrs. E.*

do point in the direction in which more positive criteria may be sought.¹⁴ These stem not from the assumption of equality of life experience, which is the contentious concept, but from the assumption that whatever his or her handicap, the radically and congenitally incompetent patient is still a person. If this assumption is true — and here only incontrovertible evidence of the permanent lack of capability for sapient cognitive awareness can count as an indication to the contrary — that patient has the same panoply of rights as all other persons. More important, it follows that he or she must be treated as a person in all respects. This in turn means that the quality of life that the patient faces in the future as well as the quality at the present time, while it may be admitted to differ in degree of sophistication from that of the competent person, nevertheless cannot be held to differ in kind: no matter what the difference in degree, the quality itself, in its very nature, must be that of a person. This, however, immediately entails that the evaluative criteria that are appropriate in the case of all other persons must be applied here as well. Not, of course, in a straightforward fashion. That would be to ignore the difference in degree between the respective qualities of life. Rather, what it means is that the physician must use the quality of life of an otherwise healthy person with similar type and degree of incompetence as an evaluative baseline and consider the relative changes that would result in that quality under the various treatment options being considered. In this it is appropriate for the physician to take into account the incompetent person's subjective expressions of satisfaction with physical life, the psychologic affect and other attendant factors and balance these against the likelihood of retention of or improvement in sapient cognitive awareness, the possibility of meaningful social interaction at that level and the cost of the various options to the patient in purely human terms. Let us call this a comparative quality-of-life coefficient. The physician must then do a similar evaluation, with due alteration of detail, for an ordinary competent patient with a similar medical problem to determine what the comparative quality-of-life coefficient would be in his or her case. The physician must then compare the two coefficients. If, on balance, the comparative quality-of-life coefficient for the incompetent patient is the same as or higher than that for the competent patient, and if in the case of the latter the decision would normally be in favour of treatment (or of some specific form of treatment), the decision must be in favour of treatment for the incompetent patient as well. If the proxy decision-maker's decision is against treatment, the physician must oppose it, if necessary through administrative and judicial channels. In all other cases, he or she need not.

This way of approaching the problem provides a procedure that can be implemented in practice. At the same time, however — or perhaps precisely because of this — it allows us to reconcile *Eve v.*


Mrs. E. with *Re Stephen Dawson*. For, in this way, Judge McKenzie's injunction to consider the situation of the radically congenitally incompetent person in the "context of the disabled person" can be given an interpretation that avoids the sophistry of substituted judgement while satisfying Mr. Justice La Forest's conclusion that the "best interests" of the person should be guiding.

A final problem

At the same time, however, the case of Eve leaves the health care professional with a problem. The considerations that I have sketched are appropriate from the perspective of the incompetent person and under the *parens patriae* powers of the court. Ethically, however, they are insufficient. Medical decisions, after all, are not made in a vacuum, nor can health care decisions be reached in isolation from the overall context in which they must be implemented. The resources that will be involved in health care decisions and their distribution have ineluctable social implications. It is here that *Eve v. Mrs. E.* fails. By being focused narrowly within the *parens patriae* doctrine as traditionally understood, the decision paints an unrealistic picture. The rights of the incompetent person must never be less than those of the competent person solely by virtue of their incompetence, to be sure. However, justice and equality demand that they not be more either. It is ethically unacceptable to engage in reverse discrimination that accords a favoured ethical status to the incompetent person solely by virtue of his or her incompetence. That, however, would in fact occur if the powers of Eve's rights, as captured in the best-interests clause as expressed in the judgement, were to be given automatic precedence over the rights of others; if, in the words of Mr. Justice La Forest, we were to "sympathize with Mrs. E." but insist, as he did, that in cases such as these only the rights of the incompetent person are decisive.¹² The point of *Eve v. Mrs. E.* and analogous court actions surely is to insist that the rights of the incompetent person must be given due weight because incompetent people are persons. That, however, also means that with due alteration of detail their rights must be treated as subject to the same balancing process to which the rights of all other persons are subject under similar conditions. By rejecting the weight of the competing rights of Mrs. E. and the rest of society, Mr. Justice La Forest has created a special class of persons who are immune from the restrictive and balancing considerations that apply to everyone else. This seems to suggest that the physician who monitors proxy decisions for such people must refrain from taking into account the considerations of equity and justice that guide the allocation of resources in all other cases. Not only are the ethics of this highly questionable, but also it may lead to a distributive nightmare.

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